



General Assembly

February Session, 2016

Raised Bill No. 5132

LCO No. 568



Referred to Committee on PUBLIC HEALTH

Introduced by:
(PH)

AN ACT CONCERNING NEWBORN SCREENING FOR POMPE DISEASE.

Be it enacted by the Senate and House of Representatives in General Assembly convened:

1 Section 1. Section 19a-55 of the 2016 supplement to the general
2 statutes is repealed and the following is substituted in lieu thereof
3 (*Effective October 1, 2016*):

4 (a) The administrative officer or other person in charge of each
5 institution caring for newborn infants shall cause to have administered
6 to every such infant in its care an HIV-related test, as defined in section
7 19a-581, a test for phenylketonuria and other metabolic diseases,
8 hypothyroidism, galactosemia, sickle cell disease, maple syrup urine
9 disease, homocystinuria, biotinidase deficiency, congenital adrenal
10 hyperplasia and such other tests for inborn errors of metabolism as
11 shall be prescribed by the Department of Public Health. The tests shall
12 be administered as soon after birth as is medically appropriate. If the
13 mother has had an HIV-related test pursuant to section 19a-90 or 19a-
14 593, the person responsible for testing under this section may omit an
15 HIV-related test. The Commissioner of Public Health shall (1)

16 administer the newborn screening program, (2) direct persons
17 identified through the screening program to appropriate specialty
18 centers for treatments, consistent with any applicable confidentiality
19 requirements, and (3) set the fees to be charged to institutions to cover
20 all expenses of the comprehensive screening program including
21 testing, tracking and treatment. The fees to be charged pursuant to
22 subdivision (3) of this subsection shall be set at a minimum of ninety-
23 eight dollars. The Commissioner of Public Health shall publish a list of
24 all the abnormal conditions for which the department screens
25 newborns under the newborn screening program, which shall include
26 screening for amino acid disorders, organic acid disorders and fatty
27 acid oxidation disorders, including, but not limited to, long-chain 3-
28 hydroxyacyl CoA dehydrogenase (L-CHAD) and medium-chain acyl-
29 CoA dehydrogenase (MCAD).

30 (b) In addition to the testing requirements prescribed in subsection
31 (a) of this section, the administrative officer or other person in charge
32 of each institution caring for newborn infants shall cause to have
33 administered to (1) every such infant in its care a screening test for (A)
34 cystic fibrosis, (B) severe combined immunodeficiency disease, [and]
35 (C) critical congenital heart disease, and (D) Pompe disease, and (2)
36 any newborn infant who fails a newborn hearing screening, as
37 described in section 19a-59, a screening test for cytomegalovirus,
38 provided such screening test shall be administered within available
39 appropriations on and after January 1, 2016. Such screening tests shall
40 be administered as soon after birth as is medically appropriate.

41 (c) On or before October 1, 2015, the Commissioner of Public Health
42 shall execute an agreement with the New York State Department of
43 Health to conduct a screening test of newborns for
44 adrenoleukodystrophy using dried blood spots, as well as the
45 development of a quality assurance testing methodology for such test.
46 The commissioner may accept private grants and donations to defray
47 the cost of purchasing equipment that is necessary to perform the
48 testing described in this subsection.

49 (d) The administrative officer or other person in charge of each
50 institution caring for newborn infants shall report any case of
51 cytomegalovirus that is confirmed as a result of a screening test
52 administered pursuant to subdivision (2) of subsection (b) of this
53 section to the Department of Public Health in a form and manner
54 prescribed by the Commissioner of Public Health.

55 (e) The provisions of this section shall not apply to any infant whose
56 parents object to the test or treatment as being in conflict with their
57 religious tenets and practice. The commissioner shall adopt
58 regulations, in accordance with the provisions of chapter 54, to
59 implement the provisions of this section.

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| This act shall take effect as follows and shall amend the following sections: | | |
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| Section 1 | <i>October 1, 2016</i> | 19a-55 |
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Statement of Purpose:

To require a screening test for Pompe disease.

[Proposed deletions are enclosed in brackets. Proposed additions are indicated by underline, except that when the entire text of a bill or resolution or a section of a bill or resolution is new, it is not underlined.]